

National Center on Birth Defects and Developmental Disabilities (NCBDDD)

# Autism Data Visualization Tool

# ABOUT 1 IN 36 CHILDREN

### WERE IDENTIFIED WITH AUTISM SPECTRUM DISORDER AMONG A 2020 SAMPLE OF 8 YEAR OLDS FROM 11 US COMMUNITIES IN CDC'S ADDM NETWORK

### ASD Data Visualization

Explore the information below to see autism spectrum disorder (ASD) prevalence estimates and demographic characteristics at the national, state, and community levels. Click on methodology to learn more about the data sources.

Accessible versions of the data presented below are available.

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# Prevalence Data

#### ESTIMATING THE PREVALENCE OF ASD

There are several ways to estimate the number of children with ASD. This estimate is referred to as prevalence, a scientific term that describes the number of people with a disease or condition among a defined group (or 'population'). Prevalence is typically shown as a percent (e.g., 0.1%) or a proportion (e.g., 1 in 1,000).

ASD prevalence estimates from the following four data sources are presented on this webpage:

Special Education Child Count NSCH Medicaid ADDM Network

Administrative data collected by the US Department of Education. The Individuals with Disabilities Education Act (IDEA) classifies children with disabilities who receive special education and related services into 13 primary disability categories, including ASD. Students 3–21 years old are eligible for services under IDEA. Under Section 618 of IDEA, states are required to report the number of students who receive special education and related services under the primary disability category for ASD. National and state-level data are available for years 2000–2019. CDC used special education child count data to report the number of children 6–17 years old with ASD who are receiving special education and related services in each state.

The National Survey of Children's Health  $\square$  (NSCH) is an annual, cross-sectional, address-based survey that collects information on the health and well-being of children ages 0-17 years, and related health care, family, and community-level factors that can influence health. The NSCH is funded and directed by the Health Resources and Services Administration's Maternal and Child Health Bureau and fielded by the US Census Bureau, using both web-based and paper and pencil methodologies, beginning in 2016. Previous survey years (2003, 2007, and 2011-12) were collected via telephone. NSCH data reflect information collected from parents/caregivers and are weighted to produce both national-and state-level estimates.

Administrative claims data from the Centers for Medicare and Medicaid Services (CMS). States report data to CMS, which releases Medicaid Analytic eXtract (MAX) datasets for analysis. CDC analyzed MAX data for each state with available data for years 2000–2012, and identified children 3–17 years old who had received Medicaid benefits and had at least two outpatient billing codes for ASD or one inpatient billing code in the specified year.

The Autism and Developmental Disabilities Monitoring (ADDM) Network is a group of programs funded by CDC to estimate the number of children with ASD and other developmental disabilities living in different areas of the United States. ADDM Network sites collect data from health and/or education records of 8-year-old children using the same methods across sites. They use these data to estimate the number of 8-year-old children identified with ASD. Community-level data are available for various communities across the United States for even-numbered years from 2000 through 2020.

Prevalence estimates can vary by type of data source because data are collected in different ways. Data collection methods differ across these sources, resulting in data gathered from various geographic locations, at different time points, among different age and racial/ethnic groups, and using different criteria to identify ASD. Because of these differences, findings typically vary across reported data sources, and it is not usually possible to compare findings.

Understanding Trends and Changes in ASD Prevalence



Ongoing monitoring and reporting help us identify trends and changes in the number of people with ASD over time. To see these trends and changes, we can look at ASD prevalence

- Across multiple years,
- Across multiple data sources,
- In different geographic locations, and
- Among different demographic groups.

These findings can be used in local communities and nationwide to inform initiatives, policies, and research that help children and families living with ASD.

### 1. REPORTED PREVALENCE HAS CHANGED OVER TIME

The reported prevalence of ASD has been higher in recent years, and this trend is consistent across data sources. It is unclear how much this is due to changes to the clinical definition of ASD (which may include more people than previous definitions) and better efforts to diagnose ASD (which would identify people with ASD who were not previously identified). However, a true change in the number of people with ASD is possible and could be due to a combination of factors. Choose a data source below to see how prevalence estimates have changed over time.

	Prevalence Estimates Over Time								
	Using data set:		etwork*	~	Show pre	valence for	U.S. or Total <sup>†</sup>	~	Apply
50									
45									
40									
35									
30									
25						•			



Note: Hover your mouse over data points above to show prevalence by year.

\*ADDM Network data only represent a selection of sites within states (but not entire states) that were funded during each project cycle;

therefore, data are not available for the entire United States.

\*\*ADDM estimate = the total for all sites combined.

<sup>+</sup>NSCH data are not comparable over time as data collection methods changed. See technical notes for further details.

<sup>++</sup>For NSCH data, data are suppressed when the width of the confidence interval exceeds 1.2 times the point estimate. This is the same

approach that is recommended by NSCH here 📙 🗹 .

<sup>+++</sup> If NSCH 2018 data are selected, combined 2016-2018 estimates are shown; if NSCH 2021 data are selected, combined 2019-2021 estimates are shown.

## 2. REPORTED PREVALENCE VARIES BY GEOGRAPHIC LOCATION

ASD prevalence varies widely across geographic areas. Currently, **no** research has shown that living in certain communities increases the chance that a child will have ASD. Geographic variation could, however, be related to differences in how children with ASD are identified and/or served in their local communities and how this information is collected and reported. Choose the data source below to see prevalence estimates by geographic area.

Prevalence	e Estimates by Geographic Area
Using data set: ADDM Network*	✓ Show prevalence for: 2020 ✓ Apply
	Prevalence by State



# 3. REPORTED PREVALENCE VARIES BY SEX

Since the first ADDM reporting period (2000), ASD prevalence has been higher among boys than girls across all ADDM sites. There are no clear explanations for this difference. One consideration is that boys may be at greater risk for developing ASD. Another consideration is that ASD can have different signs and symptoms in boys versus girls. This can contribute to differences in how ASD is identified, diagnosed, and reported. Choose the data source below to see how prevalence estimates vary by sex.

Prevalence Estimates by Sex	
Show ADDM prevalence estimates <sup>*</sup> for: U.S. or Total <sup>†</sup> V Show prevalence for: 2020 Apply	
Prevalence per 1,000 Children:	
OVERALL	27.6
BOYS	43
GIRLS	11.4
For every <b>1 GIRL</b> , <b>3.8 BOYS</b> were identified with ASD.	
*ADDM data do not represent the entire state, only a selection of sites within the state. <sup>†</sup> ADDM estimate = the total for all sites combined.	

# 4. REPORTED PREVALENCE VARIES BY RACE AND ETHNICITY

There have been racial and ethnic differences observed over the years in ADDM data. Prior to 2014, the percentage of 8year-old White children with ASD was higher than other groups. In 2014, the percentage of Black children with ASD began to be similar to White children. Asian or Pacific Islander children began to have a similar percentage of children with ASD 2016, as did Hispanic children in 2018. For the first time in 2020, the percentage of 8-year-old Asian or Pacific Islander, Hispanic, and Black children identified with ASD was higher than among 8-year-old White children. These shifts may reflect improved screening, awareness, and access to services among historically underserved groups.

Prevalence Estimates by Race/Ethnicity	
Show ADDM prevalence estimates <sup>*</sup> by race/ethnicity for: U.S. or Total <sup>†</sup> • Apply	
Non-Hispanic White Non-Hispanic Black Hispanic Asian Pacific Islander	



**Note**: *Click the icons and racial/ethnic groups above the chart to hide or unhide data. Hover your mouse over data points to show prevalence by year.* 

\*ADDM data do not represent the entire state, only a selection of sites within the state.

<sup>+</sup>ADDM estimate = the total for all sites combined.

# 5. EARLY IDENTIFICATION HAS BEEN INCREASING OVER TIME

The ADDM Network also tracks progress in early identification of ASD among children aged 4 years. When compared to children aged 8 years in the same community, it enables communities to assess whether the amount of children identified as having ASD by age 4 is increasing over time. This is measured by the cumulative incidence of ASD identification; cumulative incidence was calculated by dividing the total number of children identified as having ASD at each month of age by the entire population denominator for each age group.

Show cumulative incidence data <sup>*</sup> for:	Total†  v in: 2020  Apply
<b>Note</b> : Hover your mouse over data points to show incidence by age in m <sup>*</sup> Cumulative incidence data do not represent the entire state, only a sele <sup>†</sup> Total = the total for all sites combined.	onths. oction of sites within the state.

# Explore the Data



Now it's your turn to explore the data! Select a location from the drop-down menu below to explore ASD prevalence estimates (with the option to select a second location or data source). There is an option to view the data with or

without a confidence interval, or a range of possible values. Even though all available data will be displayed, keep in

mind that data are not available for all states across data sources.



2002
2003
2004
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2016
2017
2018
2019
2020
2021
Make selections below to view prevalence estimates by location or across data sources or to add confidence intervals.
1. Using data from: ADDM Network*
2. Add a comparison for one of the following:
Prevalence in another location: US or Totalt     Apply
O Prevalence from another data source: ADDM Network* Apply
○ Confidence interval: Hide ✓ Apply
ADDM Network estimates for overall ASD prevalence in US over time
28 US (ADDM)
26
24 E 22
a 12



\*ADDM data do not represent the entire state, only a selection of sites within the state.

\*\*ADDM estimate = the total for all sites combined.

NSCH data are not comparable over time as data collection methods changed and the data are not provided here. See technical notes for further details.

## **2020 ADDM NETWORK DATA**

In this section, explore the most recent ADDM data, both overall and among certain demographic groups by study area.

Select a location:	U.S. or Total† 🗸	Apply



#### ASD PREVALENCE PER 1,000 8-YEAR-OLD CHILDREN

#### Prevalence **Overall**

Overall: 27.6 | Lower CI: 26.9 | Upper CI: 28.3



#### Prevalence By Sex

Boys: 43 | Lower CI: 41.9 | Upper CI: 44.2





#### Prevalence By Race/Ethnicity

#### Non-Hispanic White: 24.3 | Lower CI: 23.4 | Upper CI: 25.2









# Methodology

#### WHERE DO ASD DATA COME FROM?

Different Ways to Estimate the Prevalence of ASD

There are many ways to gather data used to estimate the prevalence of ASD. These data collection methods include

• Screening and evaluating all children in a population;

- Examining data from national surveys, registries, and administrative sources; and
- Reviewing health and education records of children in a chosen population.

Each method has its advantages and disadvantages.

To learn more about different methods used to estimate ASD prevalence, as well as the advantages and disadvantages of each method, click here.

### 1. WHERE ARE ASD DATA GATHERED?

The ASD data sources included here do not all cover the same geographic areas. Some data sources include information from all states and territories. Others, such as CDC's ADDM Network, include information from specific communities or populations.

Select data source: ADDM Network*
ASD Data Collection Locations for: ADDM Network*
Since the launch of the ADDM Network in 2000, CDC has funded <b>18 sites</b> at various times. In 2020, ASD data were collected from <b>11 sites</b> by obtaining the health and education records of children with behaviors consistent with ASD.
ASD Collection Sites



Available Data from Most Recent Data Collection

No Participation or Data Suppressed

Available Data from Previous Data Collection

#### WHY THIS MATTERS

When reviewing ASD data and findings, it is important to consider *where* the data were collected and *how* each location might affect the data. Across the United States, each community has a unique population with different characteristics. There are also regional differences in healthcare and education systems, which can affect *when* and *how* children with ASD are identified, as well as the services they receive.

Because of these geographic differences, it may not be possible to directly compare data collected in one community to data from other communities. Take ADDM Network data collected from 11 sites in 2014, for example. In Colorado, ASD prevalence was 13.9 out of 1,000 kids, whereas in North Carolina, ASD prevalence was 17.4 out of 1,000 kids. There is a clear difference in the number of children identified with ASD in these two states, but without additional information, it is difficult to know *why* these differences exist. Therefore, it would not be correct to assume that the prevalence in one state will be the same as another state.

\*ADDM data do not represent the entire state, only a selection of sites within the state.

### 2. WHEN ARE ASD DATA COLLECTED?

ASD data are collected at different frequencies for different data sources. As shown below, some data sources collect data every year, while others collect data more or less frequently. These differences are due to factors like availability of funding and other resources and feasibility of data collection methods.

state: U.S. or Total <sup>†</sup>	✓ Apply			
YR	ADDM	MEDICAID	SECC	NSCH
2000				
2001				
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2004				
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2016				
2017				
2018				
2019				
2020				
2021				

Because ASD data are collected at specific times, they provide a snapshot of what was going on at a certain moment in time. Findings from different data sources are typically reported a year or more after the data were collected; therefore, prevalence may have changed between the time data were collected and the time they were reported.

\*ADDM estimate = the total for all sites combined.

# 3. **HOW** ARE ASD DATA GATHERED?

Different data sources gather ASD data in different ways. Much of the variation in reported ASD prevalence is related to these different data collection methods. The population studied and differing ASD criteria across data sources also contribute to this variation.



The ADDM Network tracks the number and characteristics of children with ASD in multiple communities in the United States. ASD prevalence could be underestimated if children have not been diagnosed or assessed for any developmental delay or if children with ASD were not enrolled in special education.

### 4. HOW CERTAIN ARE WE ABOUT THE ESTIMATES?

Scientists cannot count every person with ASD, so they *estimate* the total number (and prevalence) based on a **sample** (or a portion) collected from a specified population. For that reason, ASD prevalence is simply an estimate of the proportion of people who have ASD. For example, the prevalence of ASD in Nevada is an estimate based on a sample of the people in Nevada, not the entire population of the state.

Prevalence estimation is the best method we have to understand what is happening in the real world. However, these estimates may not be accurate. Because prevalence is an estimate based on a sample, and not the whole population, this method has some uncertainty. To show this uncertainty, researchers also calculate and report a confidence interval, or a range of possible values. If we were able to count every single person with ASD in a specified population, we should find that the *true* value falls in the range of *possible* values contained in the confidence interval. The confidence intervals reported below are 95% confident, meaning it is 95% likely that the *true* prevalence falls within the reported range of values.



about the reported prevalence.

**Note:** The graph above shows data from 2012, the most recent year for which all data sets had data.

<sup>+</sup>ADDM estimate = the total for all sites combined.

# CDC's Role in ASD Tracking

CDC has been monitoring ASD since 1996. Research and tracking have increased a great deal in recent years, and CDC is part of the larger group of public and private organizations working to better understand ASD.

Like the many families living with ASD, CDC considers ASD an important public health concern, and is committed to

- Providing essential data on ASD,
- Searching for risk factors and causes, and
- Developing resources that help identify children with ASD as early as possible.

For more than two decades, CDC has been tracking the prevalence of ASD. By tracking prevalence, CDC can find out if the number of children with ASD is rising, dropping, or staying the same. We can also compare the number of children with ASD in different areas of the country and among different groups of people. This information can help us learn about factors that might put children at risk for ASD, and can help communities direct their service and outreach efforts to those who need it most.

# Resources and Technical Notes

#### Resources

- 2020 Community Report from the Autism and Developmental Disabilities Monitoring (ADDM) Network
- CDC's Learn the Signs. Act Early. Program
- Data Resource Center for Child & Adolescent Health: The National Survey of Children's Health
- The Office of Special Education Programs (OSEP) Programs and Projects  $\square$
- OSEP's IDEA Section 618 Data Products
- Medicaid Analytic eXtract (MAX) General Information 🖸
- CDC's ASD Homepage: Links to Other Websites

#### Download accessible versions of the data presented here:

The CSV / Excel files below provide all the state-level information for ASD prevalence by state, year, and system. These data can be used for further analysis or to confirm/reproduce the data presented on this page. In the "all data" file, the "Source" variable indicates whether the data were generated by ADDM, NSCH, Special Education, or Medicaid. "Year" indicates the year the data are reporting on. "Prevalence" is the frequency of autism per 1,000 children. The "lower CI" and "upper CI" variables show the bounds of the 95% confidence interval. The "ADDM National Data" file include overall prevalence estimates and confidence intervals by sex and racial or ethnic group by year. The "ADDM State Data" file reports the same information as the "national file", but provides a separate estimate for each participating ADDM site.

- Download ADDM data 
   Also available in CSV format: ADDM National Data 
   [CSV 1 KB], ADDM State Data 
   [CSV 251 B]
- Download for all data Also available in CSV format: All Data [CSV 56 KB]
- Download for cumulative incidence data Also available in CSV format: Cumulative Incidence Data II [CSV 142 KB]

#### **Technical Notes**

#### The Autism and Developmental Disabilities Monitoring (ADDM) Network

- Comparisons across ADDM Network surveillance results should be interpreted with caution due to changing composition of sites and geographic coverage over time.
- From 2000-2016, the ADDM Network methodology involved a clinical chart review phase in which included some children with documented ASD symptoms but no documented ASD diagnosis.
- Changes in ADDM Network sites over time are outlined below:
  - <u>Surveillance Year 2000 (6 sites)</u>: Arizona (one county, including metropolitan Phoenix), Georgia (five counties in metropolitan Atlanta), Maryland (four counties and Baltimore), New Jersey (four counties, including metropolitan Newark), South Carolina (23 counties in the Coastal and Pee Dee regions), and West Virginia (statewide)
  - <u>Surveillance Year 2002 (13 sites)</u>: Alabama (northern 32 counties), Arizona (one county, including metropolitan Phoenix), Arkansas (statewide), Colorado (two counties in metropolitan Denver), Georgia (five counties in metropolitan Atlanta), Maryland (five counties, including Baltimore City), Missouri (five counties in metropolitan St. Louis), New Jersey (four counties, including metropolitan Newark), North Carolina (eight

central counties), **Pennsylvania** (Philadelphia County), **South Carolina** (23 counties in the Coastal and Pee Dee regions), **Utah** (three counties in the Salt Lake City metropolitan area), **West Virginia** (statewide), and **Wisconsin** (10 counties in southeastern Wisconsin, including metropolitan Milwaukee)

- <u>Surveillance Year 2004 (8 sites)</u>: Alabama (three counties in central Alabama), Arizona (districts in one county, including metropolitan Phoenix), Georgia (the CDC site in five counties in metropolitan Atlanta), Maryland (five counties in suburban Baltimore), Missouri (five counties in metropolitan St. Louis), North Carolina (eight central counties), South Carolina (23 counties in the Coastal and Pee Dee regions), and Wisconsin (three counties in south-central Wisconsin)
- <u>Surveillance Year 2006 (11 sites)</u>: Alabama (32 counties in north and central Alabama), Arizona (one county [Maricopa] in metropolitan Phoenix), Colorado (one county [Arapahoe] in metropolitan Denver), Florida (one county [Miami–Dade] in south Florida), Georgia (five counties in metropolitan Atlanta), Maryland (six counties in suburban Baltimore), Missouri (five counties, including metropolitan St. Louis), North Carolina (10 counties in central North Carolina), Pennsylvania (one metropolitan county [Philadelphia]), South Carolina (23 counties in Coastal and Pee Dee regions), and Wisconsin (10 counties in southeastern Wisconsin)
- <u>Surveillance Year 2008 (14 sites)</u>: Alabama (32 counties in north and central Alabama), Arizona (part of one county in metropolitan Phoenix), Arkansas (one county [Pulaski] in metropolitan Little Rock), Colorado (seven counties in metropolitan Denver), Florida (one county [Miami–Dade] in south Florida), Georgia (five counties in metropolitan Atlanta), Maryland (six counties in suburban Baltimore), Missouri (five counties, including metropolitan St. Louis), New Jersey (one county [Union] in metropolitan Newark), North Carolina (11 counties in central North Carolina), Pennsylvania (one metropolitan county [Philadelphia]), South Carolina (23 counties in Coastal and Pee Dee regions), Utah (part of one county in northern Utah), and Wisconsin (10 counties in southeastern Wisconsin)
- <u>Surveillance Year 2010 (11 sites)</u>: Alabama (nine counties in northeast and central Alabama), Arizona (part of one county in metropolitan Phoenix), Arkansas (all 75 counties in Arkansas), Colorado (seven counties in metropolitan Denver), Georgia (five counties in metropolitan Atlanta), Maryland (six counties in suburban Baltimore), Missouri (five counties, including metropolitan St. Louis), New Jersey (four counties, including metropolitan Newark), North Carolina (11 counties in central North Carolina), Utah (three counties in northern Utah), and Wisconsin (10 counties in southeastern Wisconsin)
- <u>Surveillance Year 2012 (11 sites)</u>: Arizona (part of one county in metropolitan Phoenix), Arkansas (16 counties in Arkansas), Colorado (seven counties in metropolitan Denver), Georgia (five counties in metropolitan Atlanta), Maryland (six counties in suburban Baltimore), Missouri (five counties, including metropolitan St. Louis), New Jersey (four counties, including metropolitan Newark), North Carolina (11 counties in central North Carolina), South Carolina (23 counties in coastal and Pee Dee regions), Utah (three counties in northern Utah), and Wisconsin (10 counties in southeastern Wisconsin)
- <u>Surveillance Year 2014 (11 sites)</u>: Arizona (part of one county in metropolitan Phoenix), Arkansas (all 75 counties), Colorado (seven counties in metropolitan Denver), Georgia (five counties in metropolitan Atlanta), Maryland (one county in metropolitan Baltimore), Minnesota (parts of two counties, including Minneapolis-St. Paul), Missouri (five counties, including metropolitan St. Louis), New Jersey (four counties, including metropolitan (six counties in central North Carolina), Tennessee (11 counties in middle Tennessee), and Wisconsin (10 counties in southeastern Wisconsin)
- Surveillance Year 2016 (11 sites): Arizona (part of one county in metropolitan Phoenix), Arkansas (all 75

counties), **Colorado** (seven counties in metropolitan Denver), **Georgia** (two counties in metropolitan Atlanta), **Maryland** (one county in metropolitan Baltimore), **Minnesota** (parts of two counties, including Minneapolis-St. Paul), **Missouri** (two counties, including metropolitan St. Louis), **New Jersey** (four counties, including metropolitan Newark), **North Carolina** (four counties in central North Carolina), **Tennessee** (11 counties in middle Tennessee), and **Wisconsin** (10 counties in southeastern Wisconsin)

<u>Surveillance Year 2018 (11 sites)</u>: Arizona (part of one county in metropolitan Phoenix), Arkansas (21 counties in central Arkansas), California (part of one county in metropolitan San Diego), Georgia (two counties in metropolitan Atlanta), Maryland (five counties in suburban Baltimore), Minnesota (parts of three counties in the Twin Cities metropolitan area), Missouri (five counties in metropolitan St. Louis), New Jersey (part of two counties in metropolitan New York area), Tennessee (11 counties in middle Tennessee), Utah (three counties in northern Utah), and Wisconsin (eight counties in southeastern Wisconsin)

<u>Surveillance Year 2020 (11 sites)</u>: Arizona (part of one county in metropolitan Phoenix), Arkansas (21 counties in central Arkansas), California (part of one county in metropolitan San Diego), Georgia (two counties in metropolitan Atlanta), Maryland (five counties in suburban Baltimore), Minnesota (parts of three counties in the Twin Cities metropolitan area), Missouri (five counties in metropolitan St. Louis), New Jersey (two counties in New York metropolitan area), Tennessee (11 counties in middle Tennessee), Utah (three counties in northern Utah), and Wisconsin (eight counties in southeastern Wisconsin)

#### National Survey of Children's Health (NSCH)

- The National Survey of Children's Health I (NSCH) is an annual, cross-sectional, address-based survey that collects information on the health and well-being of children ages 0-17 years, and related health care, family, and community-level factors that can influence health. The NSCH is funded and directed by the Health Resources and Services Administration's Maternal and Child Health Bureau and fielded by the US Census Bureau, using both webbased and paper and pencil methodologies, beginning in 2016. Previous survey years (2003, 2007, and 2011-12) were collected via telephone. NSCH data reflect information collected from parents/caregivers and are weighted to produce both national- and state-level estimates.
- The most recent redesign of NSCH, first conducted in 2016 and published in November 2018, included several important changes from previous survey years, such as changes to survey methods and content. Specifically, the 2016 NSCH
  - Transitioned from telephone-based administration to administration by web- and paper-based (mailed) instruments.
  - Consolidated content from two surveys (the NSCH and the National Survey of Children with Special Health Care Needs).
- The redesigned NSCH includes changes to survey questions and new content on a variety of topics related to child health.
- Survey results over time, but especially when comparing the 2016 NSCH to previous year surveys, should be interpreted with these changes in mind.
- Due to changes in the survey's mode of data collection and sampling frame it is not appropriate to compare estimates from the redesigned survey to those from previous iterations of the NSCH or NS-CSHCN or to conduct related trend analyses. The redesigned NSCH will support trend analyses in the future, beginning with data from 2016.
- For more information on the NSCH changes referenced here, please refer to the following
  - National Survey of Children's Health Questionnaires, Datasets, and Supporting Documents
  - 2016 National Survey of Children's Health Methodology Report
  - Frequently Asked Questions: 2016 National Survey of Children's Health
  - Guide to NSCH Changes Across Survey Years 🗹

#### Special Education Data (US Department of Education, Office of Special Education Programs [OSEP])

• OSEP maintains a national data source of the number of children, reported by state education departments,

receiving special education services. These services are classified into 13 primary disability categories (including ASD), which are defined under the Individuals with Disabilities Education Act (IDEA).

- The definition of ASD that is used to qualify children for special education services may differ by state.
- Prevalence numerators are derived from annual data released by OSEP ☐ for children aged 6–17 years.
   Denominators are based on public school enrollment counts for grades 1–12 using data from the National Center for Education Statistics ☐.

#### Medicaid (Centers for Medicare & Medicaid Services [CMS])

• States are required to submit Medicaid healthcare claims data to CMS annually. Upon receipt, CMS converts the state-submitted data into analytical datasets, known as Medicaid Analytic eXtract (MAX). MAX data are based on administrative claims, and have some limitations in data completeness, which may vary across states.

#### Autism Data Visualization Tool | CDC

- For this project, CDC included all available Medicaid healthcare claims data. If the prevalence in a particular state appears to be low, this may suggest that the data provided to CMS by that state were incomplete.
- The prevalence numerator is the number of children receiving Medicaid benefits with an autism ICD-9 code (i.e., 299.XX) with at least two outpatient claims or at least one inpatient claim during the year. The denominator is the total number of children enrolled in Medicaid continuously for at least three months during that calendar year.
- CDC will update Medicaid data as more recent information becomes available.

Last Reviewed: March 23, 2023